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Mothers of autistic children. How do they feel?

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Abstract

Being a parent is a difficult task. Being the parent of a child with autism is a more difficult job and a challenge. Researchers found that mothers of children with autism had higher levels of parenting-related stress (Estes, Munson, Dawson, Koehler, Zhou & Abbott, 2009). This research aims to identify how the diagnosis of autism affects the life of the mother and the whole family. Data were collected from 22 mothers of children with autism. The research method used was a questionnaire based survey with open questions. The themes derived from subjects' responses refer to the difficulty in accepting the diagnosis, the negative impact on relations between parents, and the negative attitude of society; positive aspects identified in mothers' responses refer to: hope in the recovery of their child, determination to fight to help the child. Another issue reflected by mothers' responses relates to the support of relatives, friends and experts to alleviate suffering and to continue efforts to ensure optimal conditions for the development of the child.

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1. Theoretical background

In the literature about autism, a considerable number of studies have explored issues related to parents of children with autism, the emotional states experienced by them, the coping strategies they use. Knowing how autistic disorder affects the life of the whole family and the mother's life, knowing the needs of these mothers, is a first step in formulating effective programs designed to assist them.

Autistic disorder is characterized by abnormal development, qualitative impairment in social interaction and communication, and conduct disorder (stereotypy, repetitive behaviors, non-functional rituals); these translate into a low adaptive capacity (DSM-IV-TR, American Psychiatric Association [APA], 2000).

Among the problems faced by parents of children with autism are included poor communication (rejection / avoidance and lack of understanding from family and social environment), difficulties in coping with behavior problems of children, limited social life, disagreements between parents and financial shortcomings (Papageorgiou & Kalyva, 2010). Other researchers have found maternal psychological stress, low levels of happiness in marriage,

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cohesion and family adaptability (Bromley, Hare, Davison & Emerson, 2004; Higgins, Bailey & Pearce, 2005, cited by Brown, Ouellette-Kuntz, Hunter & Kelley, 2010).

Researchers found that mothers of children with autism had higher levels of parenting-related stress (Estes, Munson, Dawson, Koehler, Zhou & Abbott, 2009). Disorder severity and age of the child are variables that are associated with maternal worry levels. Worries felt by mothers can influence them how to act in stressful situations and reduce their ability to respond effectively to their needs and the needs of children (Ogston, Mackintosh & Myers, 2011). Ogston et al. (2011) have formulated questions about the content of surveyed mothers concerns. They reported worries about the safety and child health, the significance of their dead to the child, worry about the child's educational experiences and concerns about the possibility of their child to acquire the ability to live independently and to establish relationships with others. Furthermore surveyed mothers brought into discussion the stress caused by other aspects of their lives, not related to the disorder of their child: household tasks, relationships with other people, financial resources, and job tasks. Based on these responses, the author points out that these women are not just parents of autistic children, but they fulfill different roles and have hopes, dreams and problems outside the role of a mother.

Some researches (Hastings, Kovshoff, Ward, degli Espinosa, Brown & Remington, 2005) identified some differences regarding the mental health among mothers and fathers. Mothers reported higher levels of depression. However, no statistically significant differences were obtained in terms of stress. For mothers, stress is positively associated with child behavior problems and partner depression, while for fathers there are no recorded correlations between stress and the characteristics of the child, instead the depression of the partner is a positive predictor for stress felt by them. Another interesting aspect of the mentioned research is the fact that parents also report positive perceptions about their autistic child, with a higher level of positive perceptions in regards to the mother. For the father, the depression of the mother represents a predictor for positive perceptions. The authors explain the negative effects of autistic disorder intensely felt by mothers compared with fathers, by the fact that mothers are more involved in child care and fathers use more adaptive coping strategies to reduce stress.

Based on these negative aspects with which autistic disorder is associated, researchers in the field have sought to identify factors that may have a protective role for parents of children with autism. These factors are related both to individual (hope) and the social environment (family, friends, colleagues, specialists).

The authors (Snyder, 2002) suggest that hope is a protective factor. Studies show that mothers who report high levels of hope (the ability to set and achieve goals), show a low level of worrying (Ogston, Mackintosh & Myers, 2011).

A positive relationship between parents and specialists is associated with a high level of satisfaction and a low level of stress felt by parents. Such a relation is characterized by mutual respect and communication, taking seriously the concerns of the parents, and also the parental involvement in making decisions. Studies have also identified a positive association between parental satisfaction and the quality of information on autistic disorder and post-diagnostic interventions provided by the specialist. Quality of the diagnosis of autistic disorder can be optimized through the active involvement of parents in providing both information and intervention in the education of children (Moh & Magiati, in press).

Other ways to help the parents of children with autism are the support groups. A study in Greece has identified the reasons why parents of children with autistic disorder participate in support groups: information on the latest discoveries in the field, counseling on how they should act to develop some skills to children, establishing relationships with other parents of children with autism, psychological support (Papageorgiou & Kalyva, 2010).

1. Research methodology

This research aims to identify how the diagnosis of autism affects the life of the mother and the whole family.

1.1. Participants

The participants of the present study were 22 mothers of children who were diagnosed with autism spectrum disorders (ASD), with their age ranging from 28 to 66 years old. Most mothers (19) had a boy who was diagnosed with ASD, while the rest (3) had a girl diagnosed with autism.

Although the sample is small and we can not make generalizations of the obtained data, we have considered that subjects' experiences may provide information relevant to the topic; their responses provided value to this research and represented a starting point for future studies.

1.2. Measure

The research method used was a questionnaire based survey with open-ended questions. We have chosen the questionnaire with open questions in order to not limit the freedom to respond of the mothers and to encourage the provision of significant responses to adequately reflect the feelings of the mothers of children with autism. The questionnaire included questions regarding demographic data and some open-ended questions regarding the impact of the diagnosis on the mother and the whole family, society's reactions to the child with ASD, factors that support mothers to go further, necessary qualities of mothers of children with ASD. After filling in the questionnaires, subjects' responses were qualitatively analyzed by the two authors. Recurrent ideas in the responses of participants were noted and have established codes to illustrate the expressed idea (Gibbs & Taylor, 2005).

2. Data interpretation

Regarding the impact of the diagnosis on mothers and the whole family, most of the mothers have emphasized the negative aspect: ("The news fell like a thunderbolt," "a shock for the whole family"), shattered dreams ("I gave birth to hope and I have found disappointment"), major changes in family life (parents have gone abroad for money, drugs, therapies; mother gave up work; moving to another city for kindergarten), child's rejection by the father, denial of the diagnosis, depression, neglecting the other child, disagreements between spouses ("widened the gap between me and my husband"). The answers of the mothers also indicated their negative emotions: despair, fear of changes, unhappiness, and helplessness. A small number of mothers identified positive aspects such as increased family unity, a change in a constructive manner ("the diagnosis has changed us for the better, has made us to see the world with different eyes, it made us to better understand the children with special needs and to appreciate more of their efforts and the efforts of those who support them to integrate into society"), a better knowledge of this syndrome ("I learned more about this syndrome ", "I learned what autism is").

The next question focused on how mothers perceive the reaction of society towards children with ASD. All subjects noted a tendency of individuals to marginalize the child with ASD and his family. Another common aspect in the responses of the mothers was the lack of understanding and acceptance from society. Two mothers revealed society's critical and judgmental attitudes towards the child or the mother ("ill-mannered child", "incapable mother"). The literature reports the difficulties and the embarrassment felt by parents in public places due to the behavioral problems of the child (Gray, 1993, cited by Papageorgiou & Kalyva, 2010). One subject drew attention to the indifference with which these families and their children are treated.

Factors that support parents in their efforts are of individual and interpersonal nature. Most mothers stressed the importance of hope and trust in God ("He planned something better for me, for the child, for my family"). In addition, a protective factor according to the subjects is the support from family and the support by specialists ("I met people that my child needs," "I was encouraged and advised accordingly"). A mother emphasizes the importance of collaboration between families, schools and therapists.

A final question concerned the qualities that parents of children with ASD have or should develop: patience, perseverance in making efforts to help their child, optimism, commitment, understanding to overcome the critical moments.

3. Discussion

This study enables us to better understand the feelings of mothers with children with ASD. As expected, the diagnosis of ASD is devastating for their families; most of them are facing major changes both in terms of self and in terms of relationships between family members. Marginalization, lack of understanding and acceptance, critical attitude of society comes to complicate the situation of these families. Despite the "chaos" created by the child's diagnosis, mothers find support in hope and trust in God and also in family and specialists. Professional help, reliance on family to give courage, school involvement, support mothers to act so as to improve the condition of their child. A positive aspect is that most mothers said they are determined to go further, to fight for their child.

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